



**Personal Connected
Health Alliance**

What is personal connected health?

An Ecosystem's Perspective Defining Personal Connected Health

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A HIMSS ORGANIZATION

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Introduction

“What is personal connected health?” was a question posed to the 25 key stakeholders attending a Personal Connected Health Alliance (PCHAlliance) Strategic Planning session in the summer of 2016. Two themes emerged from the participants’ responses. Most notably, personal connected health represents an evolution towards *increased personal engagement and connectivity to achieve health and wellness*. Further, this growing consumer-centric approach is *facilitated by ubiquitous technologies that improve healthcare delivery and self-health* via mobile and remote-patient monitoring devices, telehealth, and wearable technologies. In addition, all participants agreed personal connected health is a means to improve health and wellness; however, they stated that there is insufficient evidence to persuasively demonstrate how personal connected health technology can do this. They concluded that PCHAlliance should undertake a process to engage key thought leaders with complementary evidence review and market research to define personal connected health and elucidate its efficacy.

While there are some existing definitions of “connected health,” most notably one on Wikipedia and another by Accenture, these definitions are from a provider perspective. Philips’ emphasis on consumer expectations in connected health comes closer to the concept of personal connected health. PCHAlliance believes that connected health from the patient/consumer perspective is what personal connected health is about.

Over the course of the past year, PCHAlliance has engaged with over 50 key thought leaders in personal connected health to inform our understanding of this emerging and rapidly advancing movement towards ubiquitous personalized health and wellness technologies. The result of these efforts is reflected in this publication. In this first release, our focus is on developing a working definition of **personal connected health**, by including perspectives on its scope, key stakeholder groups and their interests, unrealized potential, and persistent challenges to be overcome, as well as market opportunities and challenges.

Those engaged in this process represent a broad range of geographies and expertise from the United States to the European Union to Asia, including device manufacturers and technology service providers, mobile network operators, healthcare providers, and consumer/patient advocates, along with academics and professional and industry organizations related to personal connected health.



Background: Working Definition of Personal Connected Health

To establish a working definition of personal connected health, it is instructive to begin by examining the individual words making up the term: “personal,” “connected,” and “health.”

PERSONAL: unique to a specific person — different for every individual, customized, bespoke.

per·son·al

'pɜrs(ə)n(ə)l/

adjective

1. of, affecting, or belonging to a particular person rather than to anyone else.

CONNECTED: information and communication by an individual flows seamlessly with their consent to or from a clinician, caregiver, or community.

con·nect

kə'nekt/

verb

past tense: connected; past participle: connected

1. bring together or into contact so that a real or notional link is established.
2. join together so as to provide access and communication.

HEALTH: the state of a person's physical, social, and mental well-being, including but not limited to the absence or control of a disease.

health

helTH/

noun

1. the state of being free from illness or injury.

Pulling these distinct definitions together suggests Personal Connected Health relates to elements including, but not limited to, an individual's unique characteristics and needs as well as the ability to engage with health-related information and services; and encompasses individuals taking ownership of their own health through wellness and prevention.

PCHAlliance believes an important aspect of personal connected health is the enabling nature of technology to empower the person to make sustainable health behavior change by gaining visibility or insights into physiological processes combined with other personal health information. In some cases, the technology is combined with health coaching, provider guidance, or workplace wellness incentives to teach and motivate the person to more effectively manage their health through technology. Personalization is another central principle — the connected health solution should be customized to the individual's needs, personal goals, motivation and genetic predispositions, level of health and technology literacy, and condition-specific needs. Admittedly, these capabilities are still developing.

Personal connected health technology that enables behavior change includes devices worn on the body or attached to it, those inserted into the body such as smart pills, or sensors under the skin. It also includes smart phone applications that use data generated by devices or entered by the person to manage their health. Finally, it empowers the person by providing data in a usable format.

With the foundation for a common definition, a platform for collective action can be created across the expanding greater health, technology, and advocacy ecosystems. This platform will help drive a paradigm shift from a reactive, vertical, disease-oriented focus towards a more proactive, behavior change, prevention, and wellness model based on personal connected health.

This Moment in Time — Growth in Personal Connected Health

The growth of the Personal Connected Health industry is propelled by the convergence of multiple factors, according to our thought leaders. Key trends identified were: the consumerization of health; increased cost of healthcare leading to the shift to value-based care; and the proliferation of technological and scientific innovations enabling personalized insights into health.

Consumerism has grown in many industries with the use of mobile applications for everything from travel to shopping and banking. Now it is coming to health, with growing consumer demand for applications and devices that simplify navigation of the healthcare system and offer new convenience, while providing important opportunities for engagement and self-management. Both the worried well and patients are becoming better informed, increasingly taking ownership of their health and helping to shape a new approach to healthcare delivery. This new approach makes it possible to engage all stakeholders in prevention, diagnosis, and treatment.

Patient-focused research is another driving force for personal connected health, and participants in PCHAlliance's 'definitions sessions' pointed to PCORI (Patient-Centered Outcomes Research Initiative) and the Cancer Moonshot as initiatives that have engaged patients in new ways. While great progress is being made, people do not fully trust applications as they do their doctors and want access to their own data through secure portals and applications.

Several health-specific trends are also creating a demand for personal connected health. These include lifestyle-related conditions, such as the obesity epidemic, increases in type 2 diabetes and other chronic illness, and a rapidly aging population. The economic imperatives that accompany these trends are putting focus on personal connected health as a means of decreasing the cost of care for the ill and lowering or eliminating costs via prevention. Individual health plans with high deductibles are providing financial incentive for members to take better care of their health, as an avoidance measure. As people are becoming the buyers of care, they are pushing for cost transparency and a convenient, retail experience. Value-based payment for health systems is driving a shift toward continuous monitoring through personal connected health technologies to better manage chronic disease and reduce costly emergency department visits and readmissions.

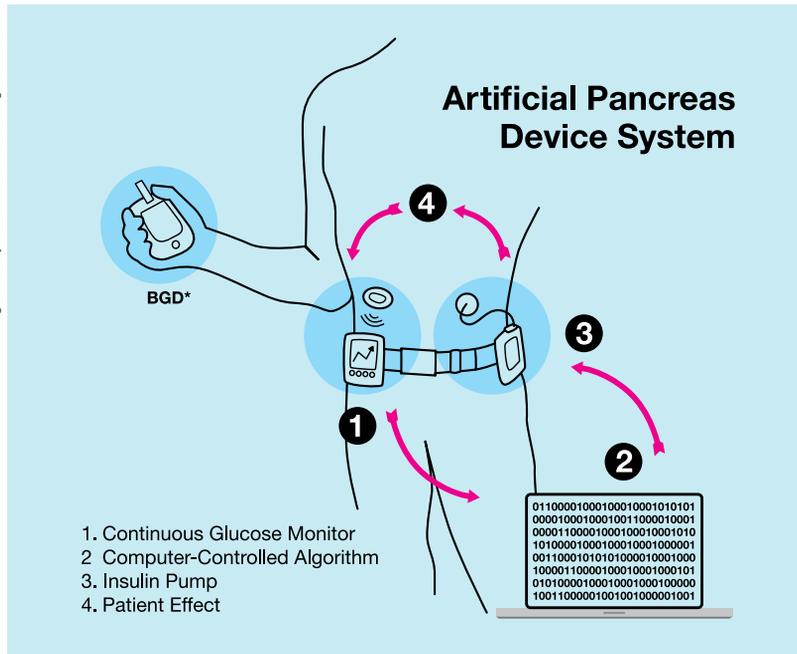
Mobile phones have become data hubs. Adoption of personal connected health devices is rapidly increasing. Data can travel to and from devices to the cloud as wireless networks become more pervasive. Cheap and increasingly miniaturized sensors enable continuous monitoring, which is often passive (easy and convenient). Predictive algorithms, built into this

“Consumers want to take responsibility for their health — 80% of New Year’s resolutions are health-related.”

Jan Oldenburg, Principal,
Participatory Health

“Personal connected health technology is expanding with the use of miniaturized sensors including transcutaneous, skin galvanometry and others to measure stress, predict seizures and more.”

Ricky Bloomfield,
MD, Director, Mobile
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“Connected health to me means my data, or some data, is going from a patient, consumer, or citizen, to some repository in the backend, and that data is either healthcare data used by a physician, or health data, which is the six steps walking across my office.”
PCHalliance Strategy Key Informant

technology, enable the patient/consumer to get immediate feedback and guidance for corrective action. These factors combined are driving rapid growth in personal connected health.

The most effective systems and applications have embedded personalization. The combined impact of data generated by a multitude of devices and from a broad range of health and non-health specific sources is creating new opportunities to gain a more holistic picture of one’s state of health. Personal health data also gives individuals the ability to maintain a state of good health or recover from a disease diagnosis. This includes environmental data related to water quality and access to healthy foods and health providers as well as more targeted genomic data.

As a best practice example, data-driven diabetes care integrates patient monitoring with treatment through a closed-loop, via a connected glucose monitor and insulin pump. One of our contributors has type 1 diabetes and has promoted this type of technology design above to help simplify a complex condition.

The Ecosystem is Everyone

Who should care about personal connected health and why?

Our thought leaders identified three distinctive types of groups they believe have an interest in personal connected health. The first group involves the individuals generating the health data. Personal connected health is ultimately about **people**. While frequently described as consumers or patients in the healthcare ecosystem, those generating personal health data are first and foremost individuals. From birth until death, health is a highly personal daily experience that is influenced by factors that are both health and non-health specific. Personal connected health must deliver tangible benefits, be targeted at individual needs, and designed in a way that connects to the individual's core values and motivations. They must generate awareness of their own body and be inspired for healthy behavior and care to be continued and sustained. Growing support for benchmarking against one's own data is helping to facilitate this movement towards increased engagement in health.

Increasingly, **caregivers** are becoming recognized by the health system. Whether they are a family member caring for a sick loved one or a paid professional, caregivers are now viewed as an essential link between the healthcare environment and the home. A segment of this group is the children of aging parents, who are increasingly engaging in the use of personal connected health tools to monitor and coordinate the care and safety of their parents at home.

Another stakeholder group involves the formal and informal **healthcare institutions (providers, payers)** receiving and leveraging patient data generated by personal connected health devices. Providers were cited by participating thought leaders as key stakeholders in personal connected health, particularly when they take the initiative to recommend devices and applications that can benefit their patients. Providers also increasingly 'prescribe' remote monitoring programs and initiate e-visits as appropriate to engage patients and track their status while at home. Large and small health systems are embracing personal connected health along with more consumer-oriented concierge practices and retail clinics.

Payers are beginning to take advantage of the opportunities afforded by personal connected health programs to improve outcomes for their members, create cost savings, facilitate solutions to problems in care delivery, and drive toward wellness. There is also recognition that personal connected health can help customers to better manage Health Savings Accounts (HSAs) and high-deductible plans through mobile apps.

“We need technology that the user can immediately engage in, that empowers and enables management of one's life.”

Casey Quinlen, patient advocate, Cure Forward Corporation

Technology and life sciences companies have also become active in adopting personal connected health. Traditional healthcare brands, like Philips and Roche are becoming digital health companies with an increased focus and interest in personal connected health. New players include health and fitness companies like UnderArmour and Fitbit, alongside big tech brands like Apple, Amazon, and Google; internet and wireless service providers and even customer relationship management companies like Salesforce, are invested in personal connected health. For these companies, there is a move towards user-centered, user-friendly, and frictionless design that provides immediate and intuitive benefits to consumers. For instance, personalized health dashboards with easy to interpret graphs of progress, make the data from wearables easily actionable. Technology companies are also looking for opportunities to create feedback loops for patients and providers. These companies are moving into the realm of predictive and prescriptive analytics through artificial intelligence, to achieve a more personalized approach to health. Pharmaceutical companies have an additional stake in personal connected health as a means of accelerating patient recruitment and capturing continuous data from subjects in clinical trials, as well as helping improve medication adherence. A proliferation of start-ups are investing in the consumer-facing digital health market in search of financial and social returns.

Other major stakeholder groups include government and policy-making and regulatory and standards bodies, patient advocacy groups, large health and consumer associations, academic institutions, venture funds, foundations, and large employers. Many employers are already using personal connect health in wellness programs to improve the health of their employees and prevent chronic conditions. Venture backers and foundations see opportunities to invest in new ideas that can both support innovation and develop new business models to sustain this change.

“It has to do with engaging individuals in their personal health and wellness management, much more than the scope of individuals who have a health problem, including individuals at risk and those who are healthy and want to stay healthy. It is about population health management, preventing people from getting ill by monitoring whatever their current health status is.”

PCHAlliance Strategy
Key Informant

Opportunities and Challenges

According to our roundtable participants, there are a broad range of opportunities in personal connected health stemming from the underlying notion that empowered individuals with insight into their health and wellness will actively engage in improving health behavior.

It is widely recognized that healthcare can and should learn from other sectors like travel, retail, and finance that have enabled frictionless, intuitive consumer experiences. Many perceive an opportunity to move health and wellness out of “healthcare” and into other aspects and settings of life: home, work, community. Incorporating knowledge and capabilities from genomics and proteomics, together with natural language processing and machine learning, can reveal insights into risk profiles and treatment options. Ultimately, the greatest opportunity is that offered by personalization of health information and experience — the intrinsic purpose of personal connected health — to improve the health of individuals and populations through insight, connection, and convenience.

The consensus of the thought leaders we polled was, for personal connected health to succeed, ethics must be considered around development of policy and regulation in cybersecurity, privacy, protection of personal health information, and access to connected care. This is a chief concern of the industry. Also of concern are regulatory frameworks for personal connected health devices and technologies, and ensuring regulation keeps pace with innovation. Although the U.S. Food and Drug Administration (FDA) recently offered some clarification, more is needed. The lack of basic telecommunications and/or health access for some populations, as is the case in some rural and lower income communities, will impede opportunities to harness the potential of personal connected health for those who are most in need.

Providers must be convinced of the value of patient-generated health data if they are to invest in connected health tools. Lack of reimbursement for connected care delivery is an enormous barrier to provider adoption. Balancing the opportunities to improve health outcomes with potential liabilities associated with personal connected health tools will be a challenge to provider adoption. Further, research into personal connected health technologies is hampered by a lack of validated methodologies, and the tools themselves have been criticized for failing to incorporate the science of behavior change into design, development, deployment, and evaluation.

Ultimately, the greatest opportunity is that offered by personalization of health information and experience — the intrinsic purpose of personal connected health — to improve the health of individuals and populations through insight, connection and convenience.

Movement Towards Personal Connected Health

Defining personal connected health is an ongoing effort — representing a convergence of thoughts, trends, and evidence — and is providing a view on what is currently possible while making room for the full aspirations of personal connected health: to make health and wellness effortless and personalized. What is clear is that it is highly multi-disciplinary and will require engagement from a multitude of stakeholder groups.

To support this, personal connected health strives to:

- improve efficiencies and reduce cost
- advance prevention over treatment
- promote individual ownership and control over personal health data, including the ability to share it with one's healthcare provider, caregivers or social network
- improve communication and data exchange between patients and providers
- create new incentives for a movement towards personal responsibility and engagement in one's own health

Success in personal connected health will be measured in a number of ways, including adoption of personal connected health tools and services; its recommended use by providers and coverage by payers; validation of improved health outcomes; increased efficiency in the health system; consumer and patient satisfaction and engagement; creation of best practices; acceptance of a health-outcomes-based business model; and ultimately a frictionless approach to health and wellness.

In the sage words of Francis Collins, MD, PhD, the Director of the U.S. National Institutes of Health, *"If you want to herd cats move the food."* The food has moved, not by the traditional healthcare industry players, but by people becoming more engaged in their health and demanding a better experience that more closely resembles their daily consumer interactions.

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